KU LEUVEN

Citation	Ismail, S.Y., Duerinckx, N. (2015), **Towards a Conceptualization of the Content of Psychosocial Screening in Living Organ Donors: An Ethical Legal Psychological Aspects of Transplantation Consensus.** Transplantation, 99(11): 2413 – 2421.
Archived version	**Post-print.** Author manuscript: the content is virtually identical to the content of the published paper, but without the final typesetting by the publisher
Published version	http://dx.doi.org/10.1097/TP.0000000000000771
Journal homepage	http://journals.lww.com/transplantjournal/pages/default.aspx
Author contact	Fabienne.dobbels@med.kuleuven.be *+ 32 (0)16 37 34 02*
IR	https://lirias.kuleuven.be/cv?u=U0015258

(article begins on next page)

Towards a Conceptualization of the Content of Psychosocial Screening in Living Organ Donors: An ELPAT Consensus

Authors

Sohal Y. Ismail,[1] Nathalie Duerinckx,[3, 4] Marieke M. van der Knoop,[1] Lotte Timmerman,[2] Willem Weimar,[2] Fabienne Dobbels,[3] Emma K. Massey,[2] and Jan J. van Busschbach,[1] on behalf of the ELPAT Psychological Care for Living Donors and Recipients Working Group[5].

Affiliations

Department of Psychiatry-Section Medical Psychology and Psychotherapy[1] and Internal Medicine-Section Nephrology & Transplantation [2], Erasmus MC, Rotterdam, The Netherlands

Department of Public Health and Primary Care, Health Services and Nursing Research, KU Leuven, Leuven, Belgium[3]

Heart Transplant Program, University Hospitals of Leuven, Leuven, Belgium[4]

Membership of the ELPAT Psychological Care for Living Donors and Recipients working group is provided in the Acknowledgments[5]

Corresponding author

Sohal Ismail, Erasmus MC, Psychiatry-Section Medical Psychology and Psychotherapy

Postbox 2040, Room GK-1252, 3000 CA Rotterdam, The Netherlands

Tel: +31 68 143 7178, Fax: +31 10 704 4695, Email: s.ismail@erasmusmc.nl

Word count

Abstract: 249, Text: 2.874

Author's contribution to work:

Participated in research design	Willem Weimar, Jan J. v. Busschbach, Emma K. Massey, Fabienne Dobbels, Sohal Y. Ismail, and Nathalie Duerinckx
Participated in the writing of the paper	Sohal Y. Ismail, Marieke M. v.d. Knoop, Jan J. v. Busschbach, Emma K. Massey, Fabienne Dobbels, Nathalie Duerinckx, Lotte Timmerman, and Willem Weimar
Participated in the performance of the research	Sohal Y. Ismail and Marieke M. v.d. Knoop
Participated in data analysis	Sohal Y. Ismail, Marieke M. v.d. Knoop, and Jan J. v. Busschbach

Funding source

This study is part of research funded by The Ethical Legal Psychological Aspects of Transplantation (ELPAT) Organization and The Dutch Kidney Foundation.

Disclosure

All authors have no other interest to disclose.

Abbreviations

Ethical Legal Psychological Aspects of Transplantation (ELPAT)

Abstract

Background: Across Europe, transplant centers vary in the content of the psychosocial evaluation for eligible living organ donors. In order to identify whether a common framework underlies this variation in this evaluation, we studied which psychosocial screening items are most commonly used and considered as most important in current psychosocial screening programs of living organ donors.

Methods: A multivariate analytic method, Concept Mapping, was used to generate a visual representation of the 'psychosocial' screening items of living kidney and liver donors. A list of 75 potential screening items was derived from a systematic literature review and sorted and rated for their importance and commonness by multidisciplinary affiliated health care professionals from across Europe. Results were discussed and fine-tuned during a consensus meeting.

Results: The analyses resulted in a six-cluster solution. The following clusters on psychosocial screening items were identified, listed from most to least important: 1) Personal resources, 2) Motivation and decision making, 3) Psychopathology, 4) Social resources, 5) Ethical and Legal factors and 6) Information and risk processing.

Conclusions: We provided a conceptual framework of the essential elements in psychosocial evaluation of living donors which can serve as a uniform basis for the selection of relevant psychosocial evaluation tools, which can be further tested in prospective studies.

Keywords: Guidelines; Kidney transplantation; Liver transplantation; Living Donation; Psychosocial; Screening

Introduction

The living kidney donor transplantation (LKDT) rates and living liver donor transplantation (LLDT) rates within Europe have been steadily increasing over the last years. A total of 3970 living organ transplantations have been performed in 2012, representing 20% of all transplantations performed. In some countries the LDKT rates now even exceed those of deceased-donor kidney transplantation (DDKT) [1]. Although living donation is a valuable solution for long waiting lists, donors undergo abdominal surgery without direct medical benefit for themselves. Therefore, special care should be provided in the pre-donation phase in order to evaluate potential adverse medical and psychosocial consequences [2-4]. Innovations in surgical techniques have brought about improvements in operation time, wound size and recovery time, which has served to limit the adverse physical consequences of donation [5-7]. However, concerns remain about the reported psychosocial consequences following living organ donation [4,8-11]. In case of specified living organ donation (to a genetically or emotionally related person directly, or indirectly via an exchange program), the potential psychosocial risks are often outweighed by the benefits of donation and although the benefits are less obvious in case of unspecified living organ donation (to an anonymous recipient), psychosocial benefits such as personal growth have been reported [8, 12-15]. In contrast, some studies reported that up to 1 out of 4 donors experience difficulties in either psychological well-being, perceived physical functioning, financial situation, or interpersonal contacts post-donation [16-18]. Mood and anxiety disorders were most frequently investigated and reported concepts [16,19-20]. In order to minimise the number of donors with psychological decomposition after donation, psychosocial evaluation has been recommended in many international guidelines [19, 21-22]. Moreover, there is growing evidence that pre-donation interventions can positively influence the well-being of living liver and kidney donors after transplantation [23].

One can distinguish psychological screening criteria for donors from the content of the psychosocial evaluation for donors. The first is used to select criteria that a donor needs to meet in order to be able to donate, while the latter reflects the content of the evaluation in order to gain understanding of the candidate and their circumstances and to identify issues that need additional monitoring and/or care. For instance, the absence of current psychosis could be an absolute selection criterion while an identified depressed mood warrants extra monitoring and consultation with a psychologist. In this paper we focus on the content of the psychosocial evaluation and not on absolute or relative (contra)indications/criteria to donation.

However, despite general agreement that psychosocial evaluation is an important component in the total work-up of living organ donors, there is currently little consensus on its content. Literature shows that transplant centers across Europe vary in the nature and extent of the psychosocial screening used for the selection of eligible living donors [22]. A recent systematic review on the pre-donation psychosocial screening practices, guidelines, protocols and consensus criteria of living kidney and liver donors revealed that there is no consensus, nor strong evidence or concrete guidance on what to screen for, leading to huge variability in screening practices [24]. The few studies which included psychosocial aspects generally lack a clear definition of the term “psychosocial” which leads to heterogeneity in terminology, concepts and operationalization of the psychosocial evaluation. Across 34 publications 196 psychosocial screening items were identified, making it hard to evaluate which are most important or effective in detecting possible psychosocial issues in donor candidates that might predict poor outcomes. Also the retrieved screening items show some overlap which calls for further reduction of overlapping or redundant items. To date there has been no attempt to collate and systematically reduce to all available screening items to measurable concepts using rigorous methodology.

Therefore this study aims to conceptualize the term ‘psychosocial’ in the context of psychosocial evaluation of living kidney and liver donors, and to categorize and reduce the number of items reported in the literature into manageable concepts and also to define to which extent each concept should be measured. We aim to close the gap between a systematic review that provided a comprehensive list of psychosocial items recommended and the future development of a tool that allows the measurement of these psychosocial screening items in living donor candidates.

Materials and Methods

Concept mapping method

Concept mapping has been used to identify important determinants/factors underlying many clinical and social problems over the past years, particularly in the development and implementation of new practical guidelines and identification of factors that contribute to important health issues such as decision making in the treatment of prostate cancer and the identification of factors that are involved in treatment adherence [25-28], reviewed in [29]. In this study the method of Concept Mapping [30-31] was used to define the concept “psychosocial” in the context of living organ donation. Concept mapping enables the creation of a visual representation of a complex topic, in which underlying concepts, their relative importance and the interplay between different concepts is organized [32]. This visual representation is the result of a combination of construct building processes (i.e. defining suitable constructs and sorting of concepts within related constructs) and multivariate analyses (multi-dimensional scaling and hierarchical clustering analyses). Concept mapping involves six phases (Figure 1) [33]. The first five steps are described in the following paragraphs. The sixth phase “Utilization of the Maps” falls beyond the scope of this paper given the focus on conceptualizing the term psychosocial rather than creating a concrete screening instrument.

The method employed has been described in greater detail elsewhere [34]. However, a summary will be provided.

Phase 1: Preparation

The first step of this phase is to define the conceptual framework that will be investigated. Here, we will focus on the conceptual framework of the term 'psychosocial' in the context of living organ donation.

Participant selection: Twenty participants including the authors and members of the psychological care workgroup and other members of Ethical Legal Psychological Aspects of Transplantation (ELPAT) Working Groups were invited to participate in phase 2 (i.e. brainstorming phase). ELPAT is part of the European Society of Organ Transplantation (ESOT). Experts in the field of transplantation in Europe who are interested in the topics addressed by one of the eight ELPAT workgroups can join ELPAT for free, under the sole condition that they are a member of the European Society for Organ Transplantation (ESOT). Working group meetings are held on an annual basis. A selected number of ELPAT members are invited by the chairs of each working group (up to 8 people per working group), based on clinical or research expertise related to topics discussed by each working group, and by ensuring interdisciplinary and broad European representation. In total 16 members participated in phase 2 which accounts for a participation rate of 80% (Table 1A). An additional 13 ELPAT members were randomly invited for the subsequent sorting and rating phase (phase 2 and 3; total number of invited participants 29). In total 26 members completed phase 3 which accounts for a participation rate of 90%. Since ELPAT is one of the leading working groups in Europe in the field of ethical, legal and psychological aspects in relation to living organ transplantation, all members are highly affiliated with clinic or research in the field of transplantation of organs from living donors. Many European countries where living organ transplantation is performed on a routine basis are represented in ELPAT (Table 1B).

According to the literature, about 10-15 participants are required to have sufficient statistical power, however, no improvement will be obtained beyond 30-35 participants [32]. Our participation number of 16 (phase 2) and 26 (phase 3) is well above the recommended minimal number of 15 [29, 35].

Phase 2: Generation of screening items

A systematic literature review was conducted, which produced an exhaustive list of screening items that might be important for screening of potential living donors [24]. This list was expanded in the brainstorming phase, asking participants to add additional screening items that might be of relevance within the donor candidate's screening. This list was reviewed and duplicate items were removed which led to a final exhaustive list of 75 potential psychosocial screening items (Supplemental file).

Phase 3: Structuring screening items

The 29 participants were asked to sort the 75 items into piles of related items. They were allowed to create as many piles as deemed appropriate based on their personal judgment and experience. Next, the participants were asked to rate the 75 items on two appraisal scales: 1) their opinion on importance of a item for donor screening, and 2) the commonness of the item used in their own clinical practice to discriminate between high and low risk donor candidates. All ratings were performed independently using a Likert scale from 1 to 7 with a higher score representing higher importance or greater commonness, respectively.

Phase 4: Representation of screening items

In this phase, all data were analyzed applying multidimensional scaling and cluster analysis using Concept Systems® computer software (Concept System Incorporated, Ithaca, New York) in order to generate the concept maps [30].

First, a similarity matrix was constructed for each sorter, to visualize which items were sorted on the same pile. These similarity matrices were then combined to a group similarity matrix, which visualized the extent to which items were sorted on the same pile at group level. Multidimensional scaling was used to create a two-dimensional plot ("point map") in which all items were represented by a point. In this point map, items that are sorted together appear closer to one other on the map compared to items that are not often sorted together.

Next, hierarchical cluster analysis was performed to partition the items in non-overlapping clusters. This process produced a map showing the overlying domains (clusters), in which the items can be categorized (a cluster map). Cluster map solutions with a total number of 5-15 clusters were analyzed according to standard guidelines [32, 37, 28, 34]. To find the optimal number of clusters in the final cluster map we performed a step-by step decrease of the number of clusters in the cluster map solution. In each step we examined which statements were grouped together and decided whether that grouping makes sense for the statements in the conceptualization. In addition, bridging values for all cluster maps were calculated. The bridging value is an expression of how often an item was originally sorted together with items in other clusters rather than items from its own cluster (ranging from 0-1). Hence, a low bridging value indicates that an item was more often sorted together with items that appear in the same cluster.

To indicate the goodness of fit of the resultant map to the original similarity matrix, a stress value was calculated (range: 0-1). A lower value indicates a better fit and reflects a strong relationship between the final cluster map and the group similarity matrix [38]. In a recent meta-analysis of previous concept mapping studies found an average stress value of 0.28 (range: 0.17-0.34) [29].

Thirdly, correlation analyses between the two rating categories (i.e. importance and commonness) were performed using Pearson correlations. These are presented as Go-Zones (see Figure 4). Go-Zones are depicted as four quadrants with two cut-off lines which are

determined by the mean importance and commonness rating and plotted on the corresponding axis. Thus those items that are rated above the average on importance and commonness can be found in the top right-hand quadrant. Correlations between these two rating categories were analyzed at cluster and item level. Psychosocial screening items with a discrepancy in commonness and importance score were identified.

All statistical analyses were performed using the software program 'The Concept Systems' (Concept Systems Inc., 2003).

Results

Participant characteristics: Twenty-six of the invited 29 participants completed the sorting and rating tasks (i.e. 90% response) (Table 1A). Professionals associated with transplant centers that are situated in 9 of the 27 EU member states and 3 of the 18 non-EU member states participated in sorting and rating tasks. The median age of the 26 participants was 40 years (range: 24-64 years), and 48% were female. These participants were psychologists, physicians, transplant nurses or a person with a law degree, and came from 13 different countries. A more detailed overview of participant`s characteristics is provided in Table 1B. The majority (70%) of the participants have been directly involved in the screening process of potential living donors. The remaining 30% of participants are either involved in the transplantation process after the screening phase or perform research on living donation.

Creating the Concept Map: Based on the sorting data, cluster maps were generated containing up to 10 clusters and main bridging values were calculated. Cluster maps of 7-10 clusters contained clusters with few items and very low coherence, decreasing the interpretability of the map. In contrast, in the five cluster solution, cluster 4 (Social resources) and 5 (Ethical and Legal) were combined, resulting in increased mean bridging values and

thus decreased interpretability. The six cluster map showed the lowest average bridging values, while remaining interpretable (Figure 2) and was thus agreed upon during the consensus meeting. To indicate the goodness of fit of this six cluster map to the original similarity matrix, a stress value of 0.31 was found; indicating a strong relationship between the final cluster map and the group similarity matrix. The following six clusters were identified and labeled: 1) Motivation and decision making, 2) Personal resources, 3) Psychopathology, 4) Social resources, 5) Ethical and Legal factors and 6) Information and risk processing (Figure 2). Clusters 1 and 2 showed the highest bridging values compared to the other clusters, indicating that these clusters contain items that are associated with items from other clusters (Figure 2). The lowest bridging values were observed for cluster 5 and 6, indicating that there was the greatest agreement during the sorting phase on the content of these clusters (Figure 2).

Rating of screening items on importance and commonness: All items were rated according to their importance and commonness. Overall there was a good correlation between both rating scales, since the clusters that are regarded as important are also commonly used in clinical practice (r = 0.77: Figure 3). This figure shows that personal resources, motivation and decision-making, psychopathology and social resources were regarded as the most important clusters. Also the two clusters personal resources and ethical & legal factors are rated as important but were, relative to their degree of importance, used less commonly in clinical practice compared to other clusters.

Since the ranking of the clusters on both scales differs, we next explored the rating of each individual item on both rating scales by computing Go-Zones for each separate cluster (Figure 4A-F). The following items were identified as important, but not commonly used in the screening of living organ donors (right lower quadrant): cluster 1: Intensity of the donor's motivation (item 18, Figure 4A); cluster 2: Ability of potential donor (and family) to cope

effectively with stresses associated with transplantation (before and after donation) (item 35) and Ability to cope with adverse outcomes for recipients (item 55, Figure 4B); cluster 3: Personality characteristics and traits (item 8, Figure 4C); and cluster 4: Ability to deal with the economic implications that may arise throughout the donation process (item 53, Figure 4D). We also identified the following items that were considered as less important, but are commonly used in screening procedures (upper left quadrant): cluster 2: Current stressors (e.g. relationships, home, work, financial) (item 41, Figure 4B); cluster 3: Current use of psychotherapeutic interventions (counselling, medication) (items 36) and Substance abuse and/or history of (item 68, Figure 4C); cluster 4: Availability of disability & health insurance (item 56) and Potential implications for donor's current job and their future insurability (item 75, Figure 4D); cluster 5: Visa status (legal presence in the country (item 7, Figure 4E). All other items showed high concordance on both rating scales and thus can be found in either the upper right or lower left quadrants of the Go-Zones. The overall correlation coefficients of the importance and commonness scores of the individual items within each cluster were as follows: cluster 1: 0.89, cluster 2: 0.87, cluster 3:0.65, cluster 4: 0.88, cluster 5: 0.83, cluster 6: 0.98. Items with above average scores on the importance and commonness scales are summarized in Table 2. These items are of particular interest in the development of screening programs.

Discussion

Literature does not provide a systematic methodology to reach a consensus about psychosocial screening of living organ donors [24, 39]. In order to facilitate consensus on the content of the psychosocial evaluation of living donors, we introduced the concept mapping method. With this study, we showed that the concept map methodology provides a practical and theoretical sound framework aimed at finding a consensus on essential screening

elements for psychosocial screening of living organ donors for research and clinical purposes. By using the input of a literature search, our concept map extents the findings of that search and provides a new point of departure in establishing guidelines for standardized screening among European transplant professionals.

Psychosocial screening items for living kidney and liver donation can be divided into six clusters. The greatest homogeneity was found for the 'Information and risk processing' cluster: professionals agree more on the content of this concept compared to other concepts. The items involving 'Personal resources' such as the ability to make own decisions (item 3), unrealistic expectations (about the process, reaction of friends and family etc.) (item 19) and vulnerability to coercion/pressure (item 42), were rated as the most important in discriminating between potential donors with high versus low risk for negative psychosocial consequences after donation. Interestingly we also identified several items that were considered as important, but are not commonly used in daily screening practice (items 8, 18, 35, 53 and 55). Importantly, most of these items are applicable to a broad group of donors. These items could receive more attention in the psychosocial evaluation of potential donors. However, in order to use these items as selection criteria, future studies are necessary to determine whether these items are predictive of poor psychological outcomes. The current literature is limited to retrospective studies and there is a need for methodologically stronger, prospective research.

Not surprisingly, items that apply to a small proportion of the donor population have lower scores on commonness. For example, cluster 5, ethical and legal factors, mainly contains items that are not commonly used, since they only apply to a small portion of the donors coming from abroad. Therefore, 3 out of 4 items are also regarded as less important. It is more important, that the foreign donor has the ability to obtain health checks after donation (item 5). Furthermore, some items may be less applicable in some European countries than in North America, such as health insurance status.

These findings should be interpreted in the light of the following limitations. An important limitation is that the sorting and rating process was done by members of ELPAT only, which may not be seen as representative for the entire clinical field. However, most European countries where living donor transplantation is routinely performed are represented within ELPAT. All members have an affiliation with living organ transplantation and the majority of members (at least 70%) are involved in the screening of potential donors. The clinical expertise of these members and knowledge on this topic is evident. Therefore, ELPAT can be considered as a group of specialists in the field of living organ transplantation. On the other hand, one can argue that the wider clinical field is neither represented in literature reviews, nor is the entire field represented in classical clinical consensus meetings. In all cases the consensus is formed by those who have a more than average interest in research, and are part of a larger scientific and clinical network. In that respect, our concept map does not differ from any other effort to arrive at a clinical consensus.

Nevertheless, it should be acknowledged that the distribution of the European participants was skewed to the Western-European countries. Although this might be a reflection of developmental stage of living donor transplantation and the amount of research on living donor organ transplantation in these countries, it is uncertain whether the results of this study can be extrapolated to Eastern or Southern European countries. If one assumes that the experts from these under-represented countries would hold different opinions, the concept map should be explored again among participants from those countries. The same holds for transplant professionals associated with transplant centers that are situated in non-EU member states. The concept mapping results, however, were presented, albeit in a non-systematic way, to professionals from Southern and Eastern European countries, and fully endorsed, suggesting that involving representatives from other countries, or adding more European countries would not significantly change our findings.

Furthermore, one can argue there is a difference in the risk profile of living liver donors and living kidney donors, warranting a separate analysis. Indeed, the psychosocial screening of living liver donors is probably more extensive than that of living kidney donors. Nevertheless, the items (and therefore the concepts) to screen for are the same. Thus we believe that the stakes are higher but potential psychosocial issues are the same in all living donors. For example the motivation to donate, the processing of the risks and social resources are of equal importance in both groups but may need to be explored in greater depth among living liver donor candidates compared to living kidney donors.

Next, although a stable concept map solution was obtained, two clusters (Ethical & Legal factors and Information and Risk processing) may be further improved considering the relatively higher variations within those concepts. A solution might be that the researcher limits the number of sorting items a priori, or provides a pre-determined list of possible sorting categories. The downside of such an approach would be that the concept mapping process would be more vulnerable to preferences of the investigators. For this reason, we only excluded items which were evidently redundant due to overlap with other items. For the same reason, items were not manually transferred to other groups in the final concept map, even if they fitted better in a different group to our opinion.

Notwithstanding these limitations, we believe that the conceptualization (i.e. clustering and rating) of the content of the psychosocial evaluation could be the first step towards the generation of an evidence-based psychosocial screening tool in future studies. A recent systematic review on pre-donation psychosocial evaluation of living kidney and liver donor candidates provided a clear overview of available psychosocial screening items [24]. We have moved forward by adding expert ratings to a carefully selected subset of these items and identified items that are regarded as important and are commonly used in the daily screening of prospective donors. However, it remains challenging to operationalize some of these items

(e.g. nr 3, 8, 9, and 42) and concrete guidance on how to measures these factors is an area for future research.

This study does not provide evidence-based screening items as the utility of these factors for predicting donor outcomes remains to be studied, but rather provides a framework/overview of concepts that are important for the psychosocial screening of living organ donors. The concept map, however, could be of guidance in the process of identifying key elements in the selection of screening items for the individual clinician for donors with an unconvincing psychosocial profile. The significance of these items should be the subject of future studies. The final product of these studies will be an evidence-based screening tool for potential living organ donors that can be used by the transplant physician in case of donors with a complex psychosocial profile. This tool might be useful in the evaluation of the prospective donors in order to estimate the amount of psychosocial care that needs to be provided to donors pre and/or post donation.

Conclusions

To our knowledge, this study is the first study that aimed to find consensus on the content of 'psychosocial screening' in the context of living kidney and liver donation in Europe, using a validated and formalized methodology. This paper moves the field of psychosocial screening forward by 1) using an approach in which all psychosocial screening items reported in the literature were initially included, refined and clustered in a manner that facilitates the further development of a tool to measure these items and 2) applying a methodologically sound and replicable approach which yielded a robust consensus on the screening of living donors. In conclusion, this paper answers the question 'What to screen for?', in a structured manner, by using an advanced and replicable method, providing the necessary basis to answer the question 'How to screen for?'.

Practice Implications

Taken together, the concept map in this study provides the first step towards 1) a uniform terminology with regard to the definition of 'psychosocial' in the context of living donation, 2) the identification of key content to be included in the psychosocial evaluation of living organ donors, for evaluating the psychosocial profile of the candidate and to estimate the need of psychosocial monitoring and/or care in the pre and/or post donation phases. Further prospective studies are necessary to test whether these factors are predictive of poor psychological outcomes after donation. In this way the donor psychosocial evaluation of prospective living donors becomes formalized and standardized, comparable to the medical screening of living donor candidates. Although the current study generates a consensus framework in the psychosocial screening of living donors, there is much work yet to be done to determine *how* best to measure these concepts.

Acknowledgements

The authors would like to acknowledge the members of the ELPAT Psychological Care for Living Donors and Recipients working group who participated in the working group meetings held in Berlin (Germany) in 2011 and Sicily (Italy) in 2012 for their contributions to this work. ELPAT Psychological Care for Living Donors and Recipients working group: Isabelle Aujoulat, Belgium; Chloë Ballasté, Spain; Ninoslav Ivanonvski, Macedonia; Ana Teresa Menjívar Hernández, Spain; Daniela Mladenovska, Macedonia; Christina Papachristou, Germany; Carine Poppe, Belgium; Ronan O'Carroll, United Kingdom; Lotte Timmerman, the Netherlands; Johan Van Gogh, the Netherlands.

We would like to thank also the members of other ELPAT workgroups who participated in the rating and/or sorting: M. Alqurashi, PhD; K. van Assche, PhD;

Prof. P. Bruzzone, PhD; I. Codreanu, PhD; F. Dor, PhD; H. El-Enin, MSc; M. Frunza, PhD; Mr P. Fryda; H. Jung, PhD; A. Lennerling, PhD; A. Luchtenburg, Prof. G. Randhawa, PhD; S. Sharma, PhD; A.N. Warrens, PhD; W.C Zuidema.

References

1. Dutch Transplant Foundation. Leiden: Nederlandse Transplantatie Stichting, 2011. http://www.transplantatiestichting.nl.
2. Middleton PF, Duffield M, Lynch SV, et al. Living donor liver transplantation–adult donor outcomes: a systematic review. Liver Transpl 2006; 12: 24.
3. Ringe B, Strong RW. The dilemma of living liver donor death: to report or not to report? Transplantation 2008; 85: 790.
4. Gökçe S, Durmaz O, Peykerlı Gürsu G, Aydoğan A, Celtık C, Ozden I, Sökücü S. 2011 Assessment of living donors with respect to pre- and posttransplant psychosocial properties and posttransplant family functioning in pediatric liver transplantation. Turk J Gastroenterol. 2011 Feb;22(1):36-41.
5. Davis CL. Living kidney donors: current state of affairs. Adv Chronic Kidney Dis 2009;16:242.
6. Fonouni H, Mehrabi A, Golriz M, Zeier M, Müller-Stich BP, Schemmer P, Werner J. 2014 Comparison of the laparoscopic versus open live donor nephrectomy: an overview of surgical complications and outcome. Langenbecks Arch Surg. 2014 Apr 28.
7. Lauterio A, Di Sandro S, Giacomoni A, De Carlis L. The role of adult living donor liver transplantation and recent advances. Expert Rev Gastroenterol Hepatol. 2014 Oct 11:1-15.
8. Clemens KK, Thiessen-Philbrook H, Parikh CR, et al. Psychosocial health of living kidney donors: a systematic review. Am J Transplant 2006;6:2965-77.
9. Dew MA, Jacobs CL. 2012 Psychosocial and socioeconomic issues facing the living kidney donor. Adv Chronic Kidney Dis. 19(4):237-43.
10. Kroencke S, Fischer L, Nashan B, Herich L, Schulz KH. 2012 A prospective study on living related kidney donors' quality of life in the first year: choosing appropriate reference data. Clin Transplant. 2012 Jul-Aug;26(4):E418-27.
11. Kroencke S, Nashan B, Fischer L, Erim Y, Schulz KH. 2014 Donor quality of life up to two years after living donor liver transplantation: a prospective study. Transplantation.15;97(5):582-9.
12. Dew MA, Switzer GA, DiMartini AF, Myaskovsky L, Crowley-Matoka M. Psychosocial aspects of living organ donation. In: Tan H,Marcos A, Shapiro R, eds. Living Donor Organ Transplantation. New York: Taylor and Francis, 2007: 7–26.
13. Lumsdaine JA, Wray A, Power MJ, Jamieson NV, Akyol M, Andrew Bradley J, Forsythe JL, Wigmore SJ. 2005 Higher quality of life in living donor kidney transplantation: prospective cohort study. Transpl Int. 2005 Aug;18(8):975-80.
14. Parikh ND, Ladner D, Abecassis M, Butt Z. Quality of life for donors after living donor liver transplantation: a review of the literature.Liver Transpl 2010; 16: 1352.
15. Rodrigue JR, Guenther R, Kaplan B, Mandelbrot DA, Pavlakis M, Howard RJ. Measuring the expectations of kidney donors: initial psychometric properties of the Living Donation Expectancies Questionnaire. Transplantation 2008;85:1230-4.
16. Dew MA, Zuckoff A, DiMartini AF, DeVito Dabbs AJ, McNulty ML, Fox KR, Switzer GE, Humar A, Tan HP 2012 Prevention of poor psychosocial outcomes in living organ donors: from description to theory-driven intervention development and initial feasibility testing. Prog Transplant. 22(3):280-92;
17. de Groot IB, Stiggelbout AM, van der Boog PJ, Baranski AG, Marang-van de Mheen PJ. 2012 Reduced quality of life in living kidney donors: association with fatigue, societal participation and pre-donation variables. Transpl Int. 2012 Sep;25(9):967-75.
18. Reimer J, Rensing A, Haasen C, Philipp T, Pietruck F, Franke GH. The impact of living-related kidney transplantation on the donor's life. Transplantation 2006;81:1268-73.
19. Tong A, Chapman JR, Wong G, de Bruijn J, Craig JC. Screening and follow-up of living kidney donors: a systematic review of clinical practice guidelines. Transplantation 2011; 92: 962.
20. Smith GC, Trauer T, Kerr PG, Chadban SJ. Prospective psychosocial monitoring of living kidney donors using the Short Form-36 health survey: results at 12 months. Transplantation 2004;78:1384-9.
21. Andrews PA, Burnapp L, Manas D, et al. Summary of the British Transplantation Society/Renal Association U.K. guidelines for living donor kidney transplantation. Transplantation 2012;93:666-73.
22. Lennerling A, Loven C, Dor FJ, et al. Living organ donation practices in Europe - results from an online survey. Transpl Int 2013;26:145-53.

23. Dew MA, DiMartini AF, DeVito Dabbs AJ, Zuckoff A, Tan HP, McNulty ML, Switzer GE, Fox KR, Greenhouse JB, Humar A. 2013 Preventive intervention for living donor psychosocial outcomes: feasibility and efficacy in a randomized controlled trial. Am J Transplant.;13(10):2672-84.
24. Duerinckx N, Timmerman L, Van Gogh J, et al. Predonation psychosocial evaluation of living kidney and liver donor candidates: a systematic literature review. Transpl Int 2013.
25. Vinson CA. 2014 Using concept mapping to develop a conceptual framework for creating virtual communities of practice to translate cancer research into practice. Prev Chronic Dis. 11:E68
26. McFall SL, Mullen PD, Byrd TL, Cantor SB, Le YC, Torres-Vigil I, Pettaway C, Volk RJ. 2014 Treatment decisions for localized prostate cancer: a concept mapping approach. Health Expect.doi: 10.1111/hex.12175. [Epub ahead of print].
27. Sjödahl Hammarlund C, Nilsson MH, Idvall M, Rosas SR, Hagell P. 2014 Conceptualizing and prioritizing clinical trial outcomes from the perspectives of people with Parkinson's disease versus health care professionals: a concept mapping study. Qual Life Res. 23(6):1687-700.
28. Rachlis B, Ahmad F, van Lettow M, Muula AS, Semba M, Cole DC. 2013 Using concept mapping to explore why patients become lost to follow up from an antiretroviral therapy program in the Zomba District of Malawi. BMC Health Serv Res. 11;13:210.
29. Rosas SR, Kane M. 2012 Quality and rigor of the concept mapping methodology: a pooled study analysis. Eval Program Plann. 35(2):236-45.
30. Trochim WMK, Kane M. Concept mapping: an introduction to structured conceptualization in health care. Int J Qual Health Care 2005;17:187-91.
31. Trochim WMK. The concept system. Ithaca: NY: Concept Systems; 1995.
32. Kane M, Trochim WMK. Concept Mapping for Planning and Evaluation. Thousans Oaks: California: Sage publications; 2006.
33. Trochim WMK, Linton R. Conceptualization for planning and evaluation. Eval Program Plann 1986;9:289-308.
34. Ismail SY, van der Knoop MM, Duerinkckx N, et al. An ELPAT definition of the concept 'Psychosocial' in the context of Screening Living Organ Donors in Europe: A Concept Mapping approach. 2012; Available from: http://hdl.handle.net/1765/38305.
35. K. Jackson, W. Trochim 2002 Concept mapping as an alternative approach for the analysis of open-ended survey responses Organizational Research Methods, 5 (4) (2002), pp. 307–336.
36. Trochim, W. M. K. (1993, November). The reliability of concept mapping. Paper presented at the Annual Conference of the American Evaluation Association.
37. Trochim WM, Cook JA, Setze RJ. Using concept mapping to develop a conceptual framework of staff's views of a supported employment program for individuals with severe mental illness. J Consult Clin Psychol 1994;62:766-75.
38. Kruskal J. B. (1964). Nonmetric multidimensional scaling: A numerical method.Psychometrika, 29, 115-129.
39. Kranenburg L, Zuidema W, Erdman R, Weimar W, Passchier J, Busschbach J. The psychological evaluation of Samaritan kidney donors: a systematic review. Psychol Med 2008;38:177-85.

Legends to figures

1. **Legend to Figure 1.** Representation of the concept mapping process organized in different phases retrieved from: Trochim WMK, Kane M. Concept mapping: an introduction to structured conceptualization in health care. Int J Qual Health Care 2005;17:187-91.
2. **Legend to Figure 2.** Point map representation of the six cluster solution. Bridging values are listed in the tables below the figure. Each number of layers corresponds to a certain range of bridging values. The more layers, the higher the bridging value of the corresponding clusters.
3. **Legend to Figure 3.** A 'pattern match' based on the concept map (7A) that shows the relationship between the rating scores at the importance and commonness scale per cluster. Horizontal lines suggest relative agreement while diagonal lines suggest relative differences. The position of the cluster names is random, although in a descending order for the respective rating. Pattern matches are especially valuable for detecting high-level patterns. Absolute values for ratings range from 1.0-7.0.
4. **Legend to Figure 4.** A bivariate 'go-zone' plot per cluster based on the six cluster solution. The quadrants are constructed using the average *x* (importance) and *y* (commonness) values. On the figures A to F the green go-zone quadrant on the upper right shows all screening items that are above average in both importance and commonness. Items which received low rating points in both plotted rating scales are located in the lower left purple quadrant. If an item received a high rating using only one of the plotted rating scales, this item is located within the orange, upper left, or yellow, lower right quadrant. The Y and X-axis represent the mean scores of the items using the corresponding rating scale. Go-zones are particularly valuable for detailing subsequent planning or evaluation efforts.

Table 1

A

Table 1A Overview of the number of participating experts in each phase of the concept mapping process				
	B	**S**	**R1**	**R3**
Invited	20	29	29	29
Finished	16	26	26	26
Legend: B brainstorming, S sorting R1 rating on importance and R3 rating on commonness				

B

Table 1B Participant characteristics (N=26)	
Age (years)	39.7 (sd 10.7)
Gender (% male)	48%
Professional background (%)	Psychologist 34.5 Physician 17.2 Lawyer 6.9 Philosopher 3.5 Sociologist 3.5 Transplant nurse / coordinator 13.8 Transplant surgeon 17.2 Ethicist 3.5
Country of employment	Belgium 13.8 Czech Republic 3.5 Germany 3.5 Italy 3.5 Netherlands 34.5 Romania 6.9 Spain 3.5 Sweden 3.5 United Kingdom 13.8 Macedonia 3.5 Moldova 3.5 Saudi Arabia 3.5 Other 3.5

Table 2 Consensus list: In conclusion, the authors and members of the psychological care workgroup reached a consensus on the following screening items driven by the Go-Zone plots:

Cluster 1: *Motivation and decision making*

1: Pressure to donate (Some kind of coercion)
2: Conflicts or dependencies in the donor-recipient relationship
3: Subordinate relationship (e.g. employer and employee)
4: Decision-making process (how the decision to donate was made)
5: Motivation/reasons for donation
6: Ambivalence

Cluster 2: *Personal resources*

1: Ability to make their own decisions / vulnerability for the reactions of others
2: Unrealistic expectations (about the process, reaction of friends and family etc.)
3: Coping strategies/mechanisms
4: Vulnerability to coercion/pressure

Cluster 3: *Psychopathology*

1: Cognitive disturbance
2: Personality disorder (e.g. paranoid, schizophrenia, borderline, narcissistic, etc.) and/or history of
3: Mood disorders and/or history of
4: Psychopathology in general (not specified which disorders and not clear if they mean current or in the past)
5: Anxiety disorder
6: Psychiatric disorders and/or history of

Cluster 4: *Social resources*

1: Financial benefit
2: Social support
3: Potential occupational risks associated with the donation
4: Potential implications for donor's current job and their future employability
5: Able to withstand time away from work or established role, including unplanned extended recovery time

Cluster 5: *Ethical and legal factors*

1: Ability to obtain health checks after donation (e.g. if the donor lives in another country)

Cluster 6: *Information and risk processing*

1: Ability to make conscious decisions
2: Ability to process information on risks/surgery
3: Comprehension/knowledge/awareness/understanding of the recipient process

4: Health concern during and after donation
5: Understanding of the right to reconsider
6: Competence to give informed consent for donation
7: Expectations of effect on relation with recipient
8: Health expectation for the recipients
9: Understanding, acceptance and respect for the specific donor protocol